

# **Guidelines for The Children's Hospital (TCH) Regional Genetics Clinics and Local Health Agencies (LHA)**

## What are TCH Regional Genetics Clinics?

### Introduction to and Purpose of TCH Regional Genetics Clinics:

- The purpose is to provide genetic diagnostic and counseling services to patients and families who do not live in the Denver-metro area. The TCH Regional Genetics Clinics allow families to access this highly specific medical specialty right in their communities.
- TCH Regional Genetics Clinics are staffed by and the responsibility of TCH
- The TCH Regional Genetics Clinics are located in various locations throughout Colorado and are scheduled several times per year at each location. Funded by Newborn Screening fees
- For more information on location of clinics, how to schedule an appointment for a clinic, specific information for clinic nearest you or any questions regarding TCH Regional Genetics Clinic services at any location please contact (303) 692-2370 or go to this website:  
<http://www.cdphe.state.co.us/ps/genetics/geneticclinics.html>

## Role of Public Health

Public health agencies and their staff working may elect to have one or more roles with TCH Regional Genetics Clinics. Each office needs to determine the level of involvement and the type of activities they engage in based on the unmet needs of families to access this type of specialty care (Genetic services) and the capacity and resources of your agency and community partners. If the local health agency (LHA) elects to have a role with TCH Genetics Clinics it can be reflected in their MCH/HCP Plan as it is an appropriate Children with Special Health Care Needs (CSHCN) systems effort. Potential public health roles are:

- Link families and primary care providers (PCPs) to TCH Regional Genetic Clinics through HCP Care Coordination
- Link families and PCP's to the TCH Regional Genetics Clinics through infrastructure activities such as provider outreach and public education
- Assess your county/region for degree of unmet need for genetic health care services
- Develop an infrastructure or sustainable system in your county/region so families have access to appropriate genetic health care services, collaborating with community partners such as PCP's, local hospitals/clinics, and TCH or others that provide genetic services

- Provide consultation and technical assistance (TA) to existing TCH Regional Genetics Clinic providers and staff on HCP Care Coordination services that are available through your office. Provide consultation and TA to TCH Regional Genetic Clinic providers on how they can link their clients to other health care and supportive services in your county/region
- Host a sustainable site location for a TCH Regional Genetics Clinic in your county/region to provide needed access to this specialty care service

#### Responsibilities for TCH Regional Genetics Clinics

The host site location and TCH each have responsibilities before, during, and after genetic clinics are held. The goal is to provide a medical home approach for coordinated health care between the family, primary care provider, and the genetic clinic specialist providers.

- TCH Regional Genetics Clinic Staff Responsibilities:

##### Pre Clinic

- Receives referrals from families and PCPs
- Schedules clinic dates at host location coordinating with host site point person
- Schedules individual appointments and coordinates with TCH Genetics providers, families, PCP's and local health agency clinic staff who host the clinic
- Coordinates and communicates with families and PCP's for any pre clinic workup, records, tests that are necessary for clinic appointment
- Informs and educates family and PCP of available genetic services through clinic
- Provides clinic schedule to host site's designated point person
- Determines and identifies other unmet family needs such as transportation, translation service, child care that are barriers for accessing TCH Regional Genetics Clinics or other needed health services
- Links families to supportive health care and community services
- Requests HCP care coordination services for individual families based on identified unmet needs or requests HCP consultation and TA on other available community resources and genetic clinic staff follows up with family Contacts families a week before clinic to remind them of clinic appointment date, time, location.
- Obtains all necessary informed consents and administrative documents to be seen in clinic including but not limited to insurance authorizations, PCP referrals and TCH registration forms.

##### During Clinic

- Greets families, orients them to clinic flow, registers them and completes all necessary administrative documents
- Performs health assessments and genetic counseling services
- Completes all documentation of clinic services , results of visit and recommendations for follow up

#### Post Clinic

- Sends clinic report with results and recommendations to families and the PCP and referral source
  - Requests HCP consultation and TA on available community resources and then provides follow up with family
  - Requests HCP care coordination services for individual families based on identified unmet needs
    - Sends a clinic report to the HCP Care Coordinator when the family has provided consent
- HCP Host site roles/responsibilities

#### Pre Clinic

- Assigns a staff member as point person for communications with TCH staff
- Obtains clinic dates, facilitates and confirms location availability
- Facilitates information to PCP's and families on TCH Regional Genetics Clinic services and how to contact TCH Genetics staff for appointment
- Obtains clinic schedule from TCH Regional Genetic Clinic staff; identifies if any clients are currently receiving HCP Care Coordination or HCP Specialty clinic services
- Posts the Regional Genetics Clinic date, site, and physician on the Google Calendar.
- HCP Specialty Clinic Coordinator facilitates sharing of HCP clinic reports with Genetic Clinic providers *for clients who are referred from HCP Specialty clinics and have a current signed HCP Specialty Clinic Consent and Release of Information Form*
- HCP Care Coordinators complete and report back on requests for HCP Care Coordination sent by TCH Regional Genetic Clinic staff

#### During Clinic

- Assigned host site personnel available as needed to help resolve unanticipated needs of TCH Regional Genetics Clinic staff such as access to Internet, room environment, etc

#### Post Clinic

- HCP Clinic Coordinator obtains and files Regional Genetic Clinic report in HCP Specialty Clinic client files when the child is the referral source to Regional Genetics Clinics by the HCP Specialty Clinic in collaboration with the PCP and there is a current signed HCP Specialty Clinic Consent and Release of Information form
- HCP Care Coordinators complete and report back on any requests for HCP care coordination sent by the TCH Regional Genetic Clinic staff